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ABSTRACT

In hospice, those who work with families have an opportunity to help the terminally ill patient and the patient's family experience death as a time for growth. There are four basic concepts of the hospice philosophy: (1) the patient and the family are the units of care; (2) physical, psychological, and spiritual needs of the patient and the family are assessed by an interdisciplinary team; (3) pain management is a cornerstone of care; and (4) there is follow-up care to help the survivors work through their emotions. Hospice workers can help to strengthen the family and the patient by encouraging family members to become actively involved in the patient's care, by affirming individual and family strengths, by bringing a calmness to the family's anxiety, and by supporting the patient's quality of life right to the end. Helpful tools for Hospice workers include a knowledge of family systems, life cycle, and death and dying literature, along with the works of Maslow, Erikson, and Kubler-Ross. Hospice workers need excellent communication skills and good listening skills. Finally, hospice workers need to be aware of the side effects of drugs used to relieve pain, and be able to help families understand these side effects. An awareness of cultural rituals associated with death, and an attitude that death is beautiful are also tools useful to the hospice worker. (NB)

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DEATH IN THE FAMILY: TRANSFORMING A TIME OF DESPAIR
INTO A TIME OF STRENGTHENING

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DEATH IN THE FAMILY: TRANSFORMING A TIME OF DESPAIR INTO A TIME
OF STRENGTHENING

In hospice, those who work with families have an opportunity to help the terminally ill patient and their family experience death as a time for growth. When the family is involved in "the caring" a time of despair has the potential to be transformed into a time for family strengthening.

This paper begins with an overview of the four basic concepts of the Hospice philosophy. Next, there is a review of some tasks that need to be considered in order to make it possible for a time of despair to be made a time for family growing and strengthening. This is followed by a discussion of some knowledge, skills, and awareness tools those working with a dying person and the family will find helpful.

I. The Hospice Philosophy - Four Basic Concepts

The first basic concept of the Hospice philosophy is that the terminally ill patient and their family are the unit of care. The second is that physical, psychological, and spiritual needs of the patient and the family are assessed by an interdisciplinary team. The third concept is that pain management is a cornerstone of care. The fourth concept is that there is follow-up care to help the survivors work

through the emotions.

4. In the medical model the patient is usually the focus of care. However, in the Hospice philosophy it is recognized that the family often experiences the same grief and emotions as the patient. Some families get lost in the medical shuffle. Some are frightened, insecure and vulnerable as the patient. Looking with Tender, p. 74

Inclusion of the family respects the fact that it is a part of life to share one another's death. When we have the opportunity to experience another's death as a natural event, accepted with calm and without fear we can refine our own religious identity. Death and Dying, p. 137

As we care for the dying person, questions arise that provide a growth mode as we search for answers. We search for answers that can give us a sense of peace and strength as we try to live our lives with meaning and purpose. In this process some of us form, enhance or strengthen our belief systems. We come to see death as an expected and integral part of life. Those of us who have been fortunate enough to share in the death of someone who understood it's meaning seem better able to live and grow because of this experience. Death: The Final Stage of Dying, p. 31, p. 119
p. 57

Within our human nature we have a great need to respond to other's needs. This urge to serve others is rooted deep within us. And in response we meet our own needs. According to Elizabeth Kubler-Ross our neglect of this is our own spiritual death.

2. After an interdisciplinary team assesses a patient's and family's needs, they develop a comprehensive and coordinated plan of care. The goal is for the dying interval (that period of time after the patient is assessed as terminal when death occurs) to be as normal, comfortable and meaning filled a time as possible for the patient and the family, and to keep the patient and family in control. Dying and Grieving, p. 159)

In this type of care psychosocial needs take precedence over medical procedures; rules bend to allow the patient to continue to do whatever s/he feels able to do or participate in. This was perhaps not the case while cure was the hope. Food and drink that may have been restricted are permitted once cure is not expected. Also welcomed are young children and pets whose presence the patient wants.

3. It is the aim of Hospice that a patient be as pain free as possible. The dosage of pain medication is determined as that amount that relieves the pain and still allows the patient to be alert enough to interact with family and visitors. In most cases today this is a realistic expectation. With pain relieved, Hospice patients customarily choose to die when the natural end appears imminent, neither prolonging life nor hastening death. (William M. Laners, Jr., M.D., Workshop)

4. Hospice provides grief and bereavement follow-up to help survivors work through their emotions. When someone we love dies, part of us goes to the grave with them. We grieve for our

may lose. Our world is diminished. Grieving is a process to recover what we have lost. . . . get back the part of us that went to the grave with our loved ones, so we can serve the whole world again. Grief is a wound and left unattended it festers. Working through grief is an integral part of the hospice way of dying.

II. Some Factors Involved in Transforming a Time of Despair into a Time for Family Strengthening.

For each hospice case the patient and family provide the hospice worker's 300 description. It will be unique for that family unit, and in establishing an environment in which opportunities for family growth and strengthening have the greatest potential for taking place the family will be involved in "the caring."

A. Active involvement in the "caring" meets the need of the family members to show love in a concrete way. More than any other force in life, involvement in death can move us to grow; that is, to become more nearly all that we truly are and at the same time become more fully human. (Death: The Final Stage of Dying, p.117)

As family members become involved in "the caring" many find a closeness and understanding that only sharing that suffering can bring. Compassionate people are ones who have known defeat, struggle, suffering, loss or have found their way out of the depths. In the process they have developed a sensitivity, appreciation and an understanding of life that fills them with compassion, gentleness and a deep loving concern. Because a bond often deepens between those who share "the caring", involvement

Hospice workers can further empower the patients and families whose lives they touch by letting them know they are our teachers. They teach us what is helpful and how to be more

skillful. Then help us validate who we are, too. (Death and Dying, p.205)

One aspect of our task is to remember a hospice worker is present not to direct this life event but to help "walk" the family through this experience using their strengths and their resources: to use their own coping mechanisms. When we do intervene with suggestions or help, it is apologetically and only when they falter. Hospice is present to help people help themselves and thus discover their own strengths.

It is important to avoid making a family feel beholden, as if they are only receivers, not givers. Hospice workers accept gracefully whatever is offered with a special awareness of cultural aspects. For example, an Oriental family may want to give a hospice worker a gift of some of the fruit given to them.

C. A third way hospice workers help the family experience their strength is to bring calmness to anxiety, a calmness that evolves out of a maturity that comes from experience, experience that is personally meaningful and thus produces trust. The hospice worker has dealt with his/her own death complex sufficiently so that s/he can help the dying person and the family overcome their anxiety and fear as death nears. Through experience hospice workers can help the family and the patient to know what to expect. Acceptance, honesty, touch, true caring can turn an otherwise frightening experience into a spirit filled experience. The unknown, the imagined is far more frightening than reality. One time I suggested a father go get his eight year old son who

was reluctant to be present when mother died. I shared with the father that coming to say good-bye could lessen emotional problems later. The child came and seeing his mother lying peacefully and naturally in the bed, he was able to say good-bye and soon reached up and held her hand. This proved to be a far less frightening experience than the child had imagined.

It is our task as to support a quality of life right up to the end. When one is given a limited life expectancy, one can make the best use of a lifetime and understanding, love and faith.

Jewish tradition is seasoned by centuries of suffering and surviving that provides a network of ways to affirm life in the face of death. Jewish tradition provides a structure that enables the expression of grief that strengthens family and community ties, that honors God, and accepts His will. One Jewish tradition is to keep the spark of hope alive. Hope need never end, but it varies:

hope for cure

hope for remission

hope for death with dignity

hope for death without pain

hope for loved ones to survive the loss (Death the Final Stage of Life, p.41)

Hospice workers can also try to support the quality of life by encouraging the patient to keep control, or at least maintain

influence in: where I die, how I die, and when I die.

Part of the "structure" for the Jewish way of dying is to encourage the dying person to get their temporal and spiritual affairs in order: to provide the family with instructions in loyalty, unity, and tradition. For people of any faith or culture there are important things to say and do before death: people to see, old disputes to deal, good-byes, forgiveness and blessings to give. When a family can get this done before the death, they are stronger.

If we know about various cultural rituals we can adapt appropriately with a sense of what will help "this" family. Families don't need to be Jewish or Indian for the rituals of these groups to be useful.

III. Helpful Tools for Hospice Workers

A. One tool is a knowledge of family systems, life cycle and death and dying literature along with a familiarity with the work of Maslow on basic needs, Erikson on the eight stages of psychosocial development, and Elizabeth Kubler-Ross' work on four quadrants of a balanced life. These theories provide hospice workers with information and insights for understanding the family's needs related to the stage of the life cycle of the family (ex. how needs will differ for a family with young children from the needs of a family with grown children who have left home). Knowledge of patterns of change and growth will enable a hospice worker a greater degree of unconditional

acceptance and that attitude will help a family work through the dying process as well as helping the dying person coming to terms with death.

A number of characteristics have been identified that families possess who deal well with involvement in "the caring". First, they appear to have contacts with community groups such as religious, professional, fraternal, and/or other organizations through which they have come to act on their own behalf to cope with life. Next, they appear to have a fluid internal organization; tasks are not gender determined, anyone can wash dishes or mow the lawn. There are flexible role relationships. Thirdly, there is shared power. Every family member is informed and participates in decision making that affects them. And lastly, there is a high degree of autonomy within the family. Relationships between members are supportive of individual growth.

However, with compassionate support family members can learn and grow as the need for changes in relationships' patterns occur. Such as when a dependent person can muster the courage to respond when the independent member of the relationship is the dying person. (Coping With Cancer, p. 83) A hospice worker also needs to be sensitive to where the family is stuck in the growth process and know where to turn for help.

Centering, imagery and visualization skills are useful in helping the patient and the family cope with stress and in working on unfinished business. Centering is a skill rooted in the ancient

tradition of meditation. It is based on conscious breathing patterns that can induce relaxation, a peaceful state, feelings of being spiritually uplifted and refreshed. Centering can produce inner quiet and tranquility.

Imagery offers vizualization scripts that help one to clarify issues troubling them, make decisions, or seek answers they have within themselves when they relax and open themselves to receive and explore their own creative responses.

One such exercise, "The Door," (Bry, p.110) brought much peace to a patient pondering her extended familys' feelings about the burden her illness put on them. The hospice worker suggested the patient think about a specific question she wanted to place on the door prior to the exercise. After centering the patient was asked to get a clear picture of "her door" in her mind. Then the patient was asked to vizualize the key words of her question in large block letters on the door. Next, the patient opened the door of her vizualization and experienced seeing her large family and friends greeting her with love. Their message was "It's all right." The vizualization brought great peace to that patient.

The connections between the state of mind and the state of the body are persuasive. Such exercises can create a milieu in which the patient and the family can respond with compassion and are more able to bear up with greater ease and dignity.

B. Another essential tool of a hospice worker guiding a patient and family through a death in the family is well honed

communications skills. To be able to listen at a level that can make a difference, a hospice worker must have worked through his/her personal pain with regard to death. (Death and Dying, p. 26) S/he needs to be able to listen without judgement and be able to respond with empathy (ex. A patient was being pressured to tell her children of her impending death, and the hospice worker's response was, "The pain of telling your children seems greater than the pain of the cancer.") This response helped to crumble the walls and masks and the patient's fears and concerns then emerged and were talked about.

When a hospice worker can "see with the eye of the heart and listen with the ear of the soul" s/he can sense a mother's regret that she will not be living to tell her daughter what she was like as a baby when her daughter becomes a mother. Thus the hospice worker might suggest that they tape that mother's memories of her child's infancy to be given to her daughter later. In the process the mother has dealt with another piece of her unfinished business.

Providing the family and patient with a form for planning the details of the funeral can help a family talk about the impending death while functioning as anticipatory grief work. As the family seek to help their dying member to say "good bye" as s/he chooses to, they also help the dying person have a sense of maintaining control of his/her dying process.

Another communications issue is that since the hospice worker is not a part of the family's system and history s/he may be more

able to pick up on symbolic and non-verbal signals. For example, a patient's question "When do most people die?", may mean "I'm ready to talk about my death" to the hospice worker who is prepared to listen to the patient's concerns surrounding his/her death, while a family member grieving the impending loss of a loved one may answer, "Mostly at night, I think.", or redirect the conversation if it is too painful for that person to talk about it.

A patient's or a family member's complaints, silence, or hostility may be experienced by a hospice worker, not caught-up in the family's dynamics, as fear or weariness. The hospice workers response can then be to empathically listen to the frightened or weary family member, giving comfort, while other family members may be unable to respond as magnanimously in these circumstances.

The family and/or the patient often want to tell the hospice worker their story. This requires a listener who wants to know what this other person is like, coupled with compassion. Once a hospice worker is perceived as "caring" and open to talking about what is important to the patient and/or the family members, the hospice worker may become a repository for family stories. With this trust a hospice worker can facilitate calls to offer forgiveness or to heal an old wound.

Good listening skills can also help the other person's words echo back to him/her and help that person to heal themselves or discover

those answers we each carry deep within ourselves. We must be able to endure silence for the beauty of silence is that it permits the experience of presence, the being totally there for another.

C. One last "tool" offered is that of awareness, awareness of the side effects of the drugs used to relieve pain. According to The Hospice Journal medication advertisements, some drugs cause moodiness, fear, anxiety, confusion, and disorientation. These symptoms are manifested in ways such as the patient regularly requesting a check on the (non-existent) people in the hall. One patient asked me if I were knitting his hair. Another said he would take his medicine when city hall opened. One patient's "rats" were shadows. A pillow on a couch caused a patient distress because the color of the pillow was similiar to his wife's hair and he was certain his wife was there, but not talking to him. Some families need help understanding these side effects in an impersonal way.

The awareness that comes from time spent exploring cultural rituals can be of great comfort to a family or a patient as you make arrangements for or are just comfortable in being included in rituals that would otherwise be unexpected or strange. Some borrowed rituals can be helpful in families who aren't Jewish, Filipino, Christian, Hawaiian, Indian, or Bhuddist, etc. These cultures' rituals and traditions have helped their people or believers survive great suffering and tragedy. The greater the

repertoire of skills and awareness one possesses the more possible it is to guide the family and patient with responses right for the particular setting. To the degree one knows the patient and family, the suggestions can be simply to sing, cry, breathe deeply, say the Rosary, form a circle of love, forgiveness, blessing, or to simply to hold each other.

It is believed by many that as death nears the dying person can receive thoughts and others can project thoughts they still wish the dying person to receive. In this way, a wife who has been unwilling to let her husband die can give him permission to die. Family members can also tend to unfinished business in this period. When survivors believe the Spirit of the patient remains near after death, this then is also a time when individuals and families can be with this person they are losing to say good-bye and clear up remaining unfinished business.

Some families welcome the opportunity to bathe the dead person and dress them for burial themselves or with the help of the hospice worker. Some plan a service at home prior to the patient's being taken away. This may be a more comfortable opportunity for children to say good-bye, and they may be more able to ask questions in private. At this time those who have participated in the care, or who have come to bid adieu, can sing and pray and launch their grief in a very healing way.

Others can launch their grief as they prepare food for those who will come to help them grieve. Some can build the coffin, and

some (in some instances) can dig the grave as the "last thing I can do for Mamma".

One last awareness to remember with regard to the patient:

if you advocate death is beautiful, remember you haven't died.

Our belief is based on theory. However, research tells us that those who have had a glimpse of death in the near death experience, no longer fear death. For family members who survive a death in the family, most find that as they helped another to say "good bye" they began to focus on beginnings intrinsic in death. For in death they discovered the journey was not over for they found the strengths developed as a part of this experience, are theirs to carry away with them.

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